Directed Deceased Organ Donation: The Problem with Algorithmic Ethics

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Introduction

The recent case of Rachel Leake, a mother who was denied a transplant using a kidney from her deceased daughter, has thrust both the Human Tissue Authority and the issue of directed organ donation back into the ethical spotlight. According to newspaper reports, Mrs. Leake has suffered from diabetes since she became pregnant with her daughter and, as a result, developed kidney failure seven years ago. She had a kidney transplant five years ago. However, the donated kidney failed last year and Mrs. Leake has been on dialysis since.[1]

Mrs. Leake's twenty-one year old daughter, Laura Ashworth, died in the intensive care unit (ICU) of the Bradford Royal Infirmary following a suspected asthma attack. Ms. Ashworth was on the Organ Donation Register and the transplant co-ordinator at the hospital became involved in her case. According to a report by BBC News, it was only after friends of Mrs. Leake's daughter said that Laura would have wanted her kidney to be donated to her mother that she approached the transplant co-ordinator with this request.[2] It was also reported that Laura had been willing to be a living donor but had not begun the formal process by which this could have taken place. UK Transplant (UKT), which has overall responsibility for co-ordination of transplant activities and the allocation of organs, appear to have referred the case to the Human Tissue Authority (HTA), which denied Mrs. Leake's request.[3] Subsequently, both kidneys and the liver of the deceased were donated to anonymous recipients.

The decision was defended by the chief executive of the HTA, Adrian McNeil, who is reported in the press as having said that:

> The central principle of matching and allocating organs from the deceased is that they are allocated to the person on the UK Transplant waiting list who is most in need and who is the best match with the donor. In line with this central principle, a person cannot choose to whom their organ can be given when they die; nor can their family.[4]

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[1] For a selection of news reports which outline the story see http://news.bbc.co.uk/1/hi/england/bradford/7344205.stm, http://www.guardian.co.uk/society/2008/apr/12/health.nhs, http://www.express.co.uk/posts/view/41126/Desperately-ill-mother-denied-daughter-s-kidney, http://www.telegraph.co.uk/news/uknews/1584782/Mother-is-denied-her-daughter%27s-kidneys.html, and http://www.timesonline.co.uk/tol/life_and_style/health/article3732210.ece. Last accessed 07 May 2008.

[2] This was reported by Mrs. Leake in an interview with BBC News. Available at http://news.bbc.co.uk/1/hi/england/bradford/7344205.stm. Last accessed 07 May 2008.

[3] http://www.telegraph.co.uk/news/uknews/1584782/Mother-is-denied-her-daughter%27s-kidneys.html and http://www.express.co.uk/posts/view/41126/Desperately-ill-mother-denied-daughter-s-kidney. Last accessed 07 May 2008.

[4] http://news.bbc.co.uk/1/hi/england/bradford/7344205.stm. Last accessed 07 May 2008.

This position was re-affirmed a couple of days later when the HTA released statement on the matter.[5]

The decision by the HTA in this case does not seem defensible and raises a number of interesting ethical questions, both on the issue and nature of directed organ donation itself and on the manner in which ethical decisions are taken. First I look at the moral permissibility of directed donation. Then I turn briefly to one of the justice claims upon which the Authority made it decision in the Leake case. And finally I draw attention to the algorithmic manner in which the decision appears to have been taken and argue that inconsistent and unjustified policy ought not to be allowed to trump common sense thinking.

Is Directed Donation Unethical?

The assumption made by the HTA in the above case is that it is unethical for an individual (prior to death) or their families (after death) to direct to whom the organs of the deceased can be donated; or to attach conditions to the donation of those organs. However, the Authority did not make their decision in isolation, but were acting in accordance with established policy. The Department of Health, in their report *An Investigation into Conditional Organ Donation,* condemned such practices. The report concluded that:

> [T]o attach any condition to a donation is unacceptable, because it offends against the fundamental principle that organs are donated altruistically and should go to patients in the greatest need.[6]

As such this has been the blanket policy on conditional donation since and the Authority could be seen as merely ensuring that it was followed.

However, the report and the ensuing policy must be put into context. The report was published following an inquiry into a case in 1998 where the relatives of a deceased man agreed to donate the organs so long as they were transplanted into a white recipient. At the time this condition was accepted and both kidneys and the liver of the deceased were transplanted. Additionally the lung tissue and pancreas were donated for use in research. The public outcry that followed led to the investigation and report by the Department of Health.

While we might find this particular case morally distasteful and be able to find reasons why this type of directed donation should not be allowed, the case of Rachel Leake gives us the opportunity to re-examine the concept and ask whether directed or conditional donation should always be considered to be morally impermissible.

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[5] HTA statement on directed donation of organs after death. 14 April 2008. Available at http://www.hta.gov.uk/newsroom/media_releases.cfm?cit_id=411&widCall1=customWidgets.content_view_1&usecache=false Last accessed 07 May 2008.

[6] Department of Health, *An Investigation into Conditional Organ Donation* (DoH: London, 2000).

We Already Allow Directed Donations

When considering the case of Rachel Leake the preliminary point that needs to be made is that *we already allow directed donations*. As Rachel Ankenny has highlighted:

> [W]hen we permit living donation, we are in fact indirectly endorsing a form of directed donation.[7]

The majority of the living organ transplants that take place in this country are kidney donations from related donors. These are donations made by one individual for the benefit of another specified person. In fact when it comes to living donation it is those individuals who would wish to make a non-directed donation to an anonymous recipient that are subjected to a high level of scrutiny.[8] It cannot be the case, therefore, that we in general and the HTA in particular, think that all cases of directed donations are in fact unethical. Why might this be?

The connection between a related living donor and recipient is a morally significant relationship. It is not one based on prejudicial judgments towards another person or class of people. The decision, therefore, to donate an organ to a relative or friend is what Harris would call a 'non-vicious' choice.[9] He argues that:

> [T]he disposition to love one's family (and one's friends) is a disposition that generally speaking makes life better all round, better for everyone.[10]

While Kluge contends that:

> If one of the primary functions of gift-giving is to create and sustain intimate relationships, and if society recognises the … relationship as being of a uniquely intimate and exceptionally desirable sort, then the very act of so recognising it creates just the special kind of relationship that ethically allows for an exception to the rule of impartial allocation.[11]

It is, however, far from clear that even in those cases where the conditions attached to donation may be 'vicious' whether or not we should completely prescribe against it. Nevertheless, a discussion of this point is outside the scope of this piece.[12]

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[7] Ankenny, R., 'The Moral Status of Preferences for Directed Donation: Who Should Decide Who Gets Transplantable Organs?' in *Cambridge Quarterly of Healthcare Ethics* (2001) 10: 387-398, p.392.
[8] Interestingly prior to the Human Tissue Authority being set up there was a specific regulatory body to deal with unrelated transplants: the Unrelated Live Transplant Regulatory Authority (ULTRA).
[9] Harris, J., *The Value of Life* (New York: Routledge, 1985), pp.71-3.
[10] *Ibid.*, pp.71-2.
[11] Kluge, E.W., 'Designated Organ Donation: Private Choice in Social Context' in *The Hastings Center Report*, 19(5) 1989: 10-16, p.13.
[12] For a wider discussion of conditional organ donation see Ankenny, R., 'The Moral Status of Preferences for Directed Donation: Who Should Decide Who Gets Transplantable Organs?' in *Cambridge Quarterly of Healthcare Ethics* (2001) 10: 387-398; Kluge, E.W., 'Designated Organ Donation: Private Choice In Social Context' in *The Hastings Center Report*, 19(5) 1989: 10-16; and Wilkinson T.M., 'What's Not Wrong with Conditional Organ Donation?' in *Journal of Medical Ethics* 29, 2003: 163-4.

The Greatest Need

Perhaps then it was not a concern with the motives involved in the Mrs. Leake's request that prompted the HTA to deny her the transplant, but one of justice. The report by the Department of Health in 2000, the statement by the Authority's Chief Executive, the subsequent press release from the Authority all claim that deceased donor organs are allocated on the basis of 'greatest need'. Again we find a dissonance with the permitted system of living donation. Here we do not champion those at the top of the UK Transplant waiting list or claim that they are the ones most in need of the transplant. I imagine it would be the cause of some outrage if the transplant co-ordinator were to tell the living donor after the operation that his organ had not in fact been transplanted into his relative or friend but into another recipient as 'their need was greater'. It is almost certain that the only reason most living donations take place is precisely because they are *directed* towards their relative that they care about and this is permitted regardless of the 'greater need' of others. As Kluge points out:

> Family ties, then, are uniquely privileging and identifying, and designated organ donation occurring within the immediate family context does not violate the equality-and-justice condition.[13]

Algorithmic Ethics or Common Sense?

One might point out that these criteria set out by the HTA are meant to apply to deceased and not living donations. Given that this is the case we must ask are there any morally relevant reasons that distinguish between deceased and living donations and that lend themselves to governing these donations by two different sets of moral principles: one system where the concepts of relatedness and family ties permit the donations to be directed and to trump the greatest need criterion, and the other where they do not. I, for one, cannot think of a reason that would support this dichotomy.

It seems that for the sake of moral consistency that there are two options available. The first would be to decide that the principles of non-directed donation and greatest need really are the ones that should unfalteringly guide the United Kingdom's system of organ donation. If this were to be the case then our scheme for living donations ought to be brought into line with that for deceased donations. Donations that are directed towards relatives and friends would no longer be permitted and those organs (mostly kidneys) that are procured would go to those at the top of the waiting list in the 'greatest need'.[14] Such a system, of course, would have an impact on the numbers of organs procured, with the most likely result being a significant decrease in organs for transplantation. It is unlikely that the HTA truly believes that non-directed donation and greatest need really are inflexible principles and this is shown by the fact that they are now considering whether the rules in this area should be changed.[15]

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[13] Kluge, *op. cit.*, p.12.

[14] Of course the assumption that it is those at the top of the waiting list that are in fact in the greatest need is contestable, but that is a task for another paper.

[15] [15] HTA statement on directed donation of organs after death. 14 April 2008. Available at http://www.hta.gov.uk/newsroom/media_releases.cfm?cit_id=411&widCall1=customWidgets.content_view_1&usecache=false Last accessed 07 May 2008.

This leads us to the second option which is to recognise that not all forms of directed donation are morally reprehensible. The fact that we do not consider directed living donation to be unethical supports this. If the kinds of factors, such as relatedness and family ties, which would permit directed living donation also exist some exceptional cases involving deceased individuals, then those self same factors should also count for permitting directed donation in those cases. It is clear that the case of Rachel Leake is more analogous to the normal living donation scenario than it is to the usual deceased donation ones. Here we have a situation where Laura Ashworth had been willing to donate a kidney to her mother, but fate intervened before this could take place. Her support for organ donation in general was patent from the organ donor card that she carried. This in addition to her willingness prior to death to donate to her mother ought to have prompted the HTA to allow one of her kidneys to be used commensurate with her wishes.

In this and similar cases it would have been legally permissible to allow the donation to be directed, it was simply a matter of policy that it was not.[16] However, the quick application of a policy that was actually intended to stop racially motivated conditions being attached to the donation process led to the wrong decision being made in Mrs. Leake's case. In order to be responsive rather than inflexible policy ought to guide not be absolutely binding. And when regulatory bodies make what are essentially moral decisions they should take care to ensure that common sense thinking triumphs over the algorithmic application of inadequately considered and unjustified policy that parades as ethical principles.

[16] The Human Tissue Act 2004 which governs the area of donation and transplantation does not make directed illegal.